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Identifying People with Dementia on Twitter

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Abstract

There is a growing body of research on the use of Twitter by people with health conditions, but it does not include people with dementia. In this brief report we aim to: (1) determine whether people with dementia are using Twitter; (2) provide an estimate of the number of Twitter account holders who identify as having a diagnosis of dementia; and (3) examine the demographic characteristics of these account holders. Tweetcatcher was used to identify tweets containing the search terms ‘dementia’ or ‘Alzheimer’. These data were systematically searched to locate account holders who identified themselves as having a diagnosis of dementia, and a content analysis was conducted of these account holders’ profiles. Thirty account holders self-identified as having a diagnosis of dementia. The average age of account holders was 59 years and the majority were located in North America or the UK. Although the majority of account holders reported having Alzheimer’s disease or did not specify a type of dementia, some rare forms of dementia were also evident. The sample consisted of relatively young account holders and contained more men, which might suggest that other groups are under-represented on Twitter. The majority of account holders considered themselves a dementia activist or were affiliated with a dementia organisation. The findings suggest that people with dementia, with varying demographic characteristics and a range of diagnoses, are active on Twitter. These account holders are more frequently male, relatively young, and dementia activists.

Introduction

In recent years, dementia research has moved beyond stereotypical assumptions and biomedical models to embrace approaches that consider the whole person (Kitwood, 1997). Previously, people with dementia were considered to be ‘victims’ (Fontana & Smith, 1989) who experienced a ‘loss of self’ (Cohen & Eisdorfer, 1986) and a ‘living death’, but the personhood approach has championed the value of the lived experience and framed people with dementia as service users, consumers, and people with rights who can ‘live well’ with dementia (Clare et al, 2014; Innes, Archibald, & Murphy, 2004; Kirman, 2006; Rahman, 2014; Wiersma, O’Connor, Loiselle, 2016). Encouraged by this shift in attitudes, people with dementia have begun to acknowledge their rights and seek opportunities to advocate for themselves (Bartlett, 2012, 2014). Research suggests that people with dementia are using the internet to access social media platforms such as Facebook, blogs, and forums to facilitate their activism, seek support, share information, and connect with others (Clare, Rowlands, & Quin, 2008; Craig & Strivens, 2016; Lorenz, Comas-Herrera, Knapp, & Damant, 2017; Rodriquez, 2013). To our knowledge, however, there has been no research on how people with dementia use the social networking site Twitter.

In other health conditions, people have used Twitter for information-sharing, social support, raising awareness, and advocacy (Berry et al, 2017; Hemsley, Dann, Palmer, Allan, & Balandin, 2015; Himelboim & Han, 2014; Tsuya, Sugawara, Tanaka, & Narimatsu, 2014; Gabarron, Makhlysheva, & Marco, 2015). Similarly, Twitter hashtags, such as #blacklivesmatter and #freethenipple, have also been used to further the social movements of oppressed or under-represented groups (Bassett, 2015; Highfield, 2016; Rossado & Marques, 2016). Twitter might, therefore, provide a platform for people with dementia, who have traditionally been marginalised within society (Gilmour & Brannelly, 2010), to communicate their experiences and perspectives.

The demographic and diagnostic information of Twitter users with health conditions can provide important information about the voices that are represented on this platform. The prevalence of dementia in the general population is greater for women (Alzheimer's Research UK, 2015) and yet the voices of women affected by dementia are often missing from research (Bartlett, Gjernes, Lotherington, & Obstefelder, 2016). Previous research on Twitter users with a diagnosis of cancer has found that men and women are equally represented on Twitter and use the platform to tweet about a range of cancer types (Sugawara et al, 2012). To our knowledge, there has been no research on the demographics of Twitter users with dementia. It is unclear whether certain groups of people with dementia, such as women and people with rare types of dementia, are also underrepresented on Twitter or if the platform provides a more equitable space for the voices of all people with dementia to be heard.

The aims of this brief report were to: (1) determine whether people with dementia are using Twitter; (2) estimate the number of Twitter account holders who publicly identify as having a diagnosis of dementia; and (3) examine the demographic characteristics of these account holders. The study was approved by the Human Research Ethics Committee of the University of Exeter Medical School.

Method

Data collection

On 12th June 2017 16:42 (GMT), the data extraction software programme Tweetcatcher, which uses Twitter's Search Application Programming Interface (API) to identify past tweets using predefined keywords (Brooker, Barnett, & Cribbin, 2016), was used to identify tweets posted in the previous 24 hours that contained the search terms 'dementia' or 'Alzheimer'. It is not currently possible to search for Twitter account holders

by their profile description, only by their tweets, so this is the only viable method of collecting Twitter data (Kumar, Morstatter, & Liu, 2014). Once the tweets are located, it is then possible to examine the profiles of the account holders who posted them.

The search was repeated every 24 hours for 30 consecutive days. For each tweet, the contents of the tweet and the date and time of posting were collected. The following information was collected from the Twitter profile of the account holder who posted the tweet: username, real name, location, 'bio' (Twitter, 2017a), number of tweets, number of followers, and number being followed.

Sample

Tweetcatcher identified 416,826 tweets containing the terms 'dementia' or 'Alzheimer' during the 30-day period. This included 226,602 retweets. The sample was screened for multiple tweets by the same account holder, reducing the final sample to 217,623 tweets (including 132,628 retweets).

Tweets and account holder data were imported into Microsoft Excel for analysis. The profile descriptions of the account holders were searched for any evidence of a dementia diagnosis. A systematic search strategy was developed by the first author and included the following: statements of having a diagnosis (e.g. 'I have dementia', 'diagnosis' AND 'dementia'); different types of dementia (e.g. 'frontotemporal'); and campaigns or groups led by people diagnosed with dementia (e.g. "Scottish Dementia Working Group", "SDWG"). Account holders were excluded from the sample if they belonged to organisations, were researchers or carers, or were individuals who did not identify as having dementia. For practical reasons, only accounts written in English were included.

Data Analysis

A content analysis was conducted to identify characteristics of the sample. In a content analysis, large quantities of text are organised into fewer content categories. These categories refer to patterns or themes that are directly expressed in the text or derived through the analysis (Marks & Yardley, 2004). Codes for content were gender, current age, age at diagnosis, type of dementia, description of dementia, advocacy activities, affiliations with dementia organisations, and social identities beyond the dementia diagnosis. ‘Description of dementia’ referred to how the account holders described their condition, such as ‘living with dementia’ or being a ‘dementia patient’. ‘Social identities beyond the dementia diagnosis’ referred to other social roles account holders occupied beyond their identities as people with dementia. Descriptive analyses were conducted to identify the relative frequency of each content category.

Results

Of the 217,624 account holders tweeting about dementia, thirty publicly identified themselves as having a diagnosis of dementia. The average age was 59 years (range: 37–88), they had been on Twitter for an average of five years, and the majority were men. The full list of demographic characteristics is reported in Table 1.

Table 1. *Participant demographics.*

Characteristic	Mean (SD)	Range	N
Time since first joined Twitter (years)	4.57 (2.61)	0–9	
Number of tweets	13,900 (286,000)	82–130,932	
Number of followers	1930 (2330)	44–8337	
Number following	1406 (1715)	50–7462	
Age (years)	58.6 (15.8)	37–88	7
Age at diagnosis	51.3 (1.77)	50–52.5	2
Gender			
Male			17
Female			12
Unknown			1
Location			
UK and Ireland			15
North America			12
Australia			1
Unknown			2

The majority of account holders ($n=20$) specified the type of dementia with which they had been diagnosed, with Alzheimer's disease being the most common (see Table 2).

Table 2. *Twitter account holders self-reported type of dementia.*

Type of dementia	N
Not specified	12
Alzheimer's disease	8
Lewy body dementia	3
Posterior cortical atrophy	2
Frontotemporal dementia	2
Mixed dementia	1
Atypical Alzheimer's disease	1
Vascular dementia	1

Eight Twitter account holders described themselves as having young-onset dementia (i.e. onset of symptoms before the age of 65). Two account holders gave their ages at the time of diagnosis, which were 50 and 52.5, respectively.

Although descriptions of dementia varied considerably, the majority of account holders ($n=16$) described themselves as 'living with' or 'living well with' dementia. Other descriptions included 'having a diagnosis' of dementia ($n=4$), 'having' dementia ($n=3$), 'person with' dementia ($n=1$), and being a 'dementia survivor' ($n=1$). One female account holder described herself as a 'patient'.

Seven account holders identified themselves as dementia activists/advocates, and 10 were affiliated with an organisation such as the Scottish Dementia Working Group, the Three Nations Dementia Working Group, or the European Dementia Working Group.

Fourteen account holders reported social identities beyond their dementia diagnosis. These included father, football fan, and animal lover.

Discussion

To our knowledge, this is the first study to examine the use of Twitter by people with dementia, and the results clearly show that people with dementia are active on Twitter. Eight account holders reported having young-onset dementia, the average age of account holders was 59 years, the average age at diagnosis was 51 years, and the majority were located in North America or the UK. Although Alzheimer's disease was most commonly reported, a range of diagnoses was evident, including rare forms of dementia such as posterior cortical atrophy. The majority of account holders reported 'living with' dementia and considered themselves a dementia activist or were affiliated with a dementia organisation. Only 40 percent of the account holders identified in this study were female.

Although the population identified in this study is relatively small when compared with the organisations, health professionals, and general public who contribute to dementia-related content on Twitter (Robillard, Johnson, Hennessey, Beattie, & Illes, 2013; Oscar et al, 2017), it is likely to increase as digital natives and immigrants age (Prensky, 2001). Social media platforms such as Twitter are expected to become an integral aspect of living with dementia as 'tech-savvy' generations approach later life, and this is already evident in the relatively young age of the sample in this study. Twitter and other social media platforms may be changing the lived experience of dementia by facilitating greater social connection, engagement, and self-expression than has been possible for pre-Web 2.0 cohorts.

Previous research on the use of social media by people with dementia has either not specified the type of dementia (Lorenz et al, 2017; Rodriguez et al, 2013) or has focused on people diagnosed before the age of 65 (Craig & Strivens, 2016). The current study provides evidence that people with a range of different dementia diagnoses are active on Twitter. Although the majority of account holders reported having Alzheimer's disease or did not

specify their diagnosis, other types of dementia (including rare forms of dementia) were evident. This could be because people under the age of 65 are more likely to be diagnosed with a rare type of dementia (Dickerson et al, 2017), such as posterior cortical atrophy, and are also more likely to use Twitter (Greenwood, Perrin, & Duggan, 2016).

The range of dementia types identified in this study echoes the findings of Sugawara et al. (2012) which showed that people with a range of cancer types, such as breast, stomach, prostate, and liver cancer are active on Twitter. People with different types of dementia could use Twitter for different reasons and gain different benefits from it. People with rare forms of dementia, for example, might use Twitter to share their experiences with a wider audience and to raise awareness of non-Alzheimer's conditions, while those with more common forms of dementia might use it for social support or information seeking. Although it is beyond the scope of this study, research that examines the tweets of people with different types of dementia could be used to identify differences in the Twitter behaviour of those with rare and common conditions and those with young and later onset.

The majority of account holders in this study were men and were relatively young, yet the prevalence of dementia in the general population is greater for women and people over the age of 65 (Alzheimer's Research UK, 2015; Prince et al, 2014). This finding contrasts with the findings of prior research regarding the use of Twitter by people with cancer, where men and women were equally represented on the platform (Sugawara et al, 2012). It is possible that, despite its potential for giving voice to the marginalised and oppressed, Twitter might not be providing a platform for all people with dementia. Instead, the dominance of younger and male dementia voices on Twitter might be perpetuating the marginalisation and stigma experienced in 'real life', especially by older women with dementia. This could also be reflective of the demographics of Twitter users, where those over the age of 65 make up the smallest proportion of account holders (Greenwood et al, 2016).

In this study, the diagnosis of dementia was self-reported in Twitter ‘bios’, so it was not possible to identify the stage of dementia or the type of impairments account holders are living with. Although it is likely that it is mainly people with less severe dementia who are using Twitter, this can only be confirmed through research that moves beyond data collected solely from Twitter and engages with account holders directly. Similarly, dementia is a progressive condition, and although this study provides an important snapshot of the demographic characteristics of current Twitter account holders who identify themselves as having a diagnosis of dementia, it does not describe how the use of Twitter by people with dementia changes as their condition progresses. The use of longitudinal methods in future research could make it possible to examine this.

It is interesting to note that although descriptions of the experience of dementia varied, none of the account holders described themselves as ‘suffering from’ dementia, and only one used the term ‘patient’. This may reflect the growing emphasis on personhood in dementia research and practice, which frames people with dementia as individuals who are more than their diagnosis and can live well with the condition (Kitwood, 1997). Although it was beyond the scope of this study, future research could examine whether people with dementia are using Twitter to challenge stereotypical beliefs and further their social movement.

The majority of account holders described themselves as dementia activists and/or were affiliated with a dementia organisation. This suggests that these account holders could be using Twitter to facilitate their activism and further their social movement, just like account holders who use hashtags relating to other issues (Bassett, 2015; Rosado & Marques, 2016). This finding is also consistent with research on the use of other social media platforms (e.g. blogs and forums) by people with dementia, which has also identified advocacy activities as important (Clare et al, 2008; Lorenz et al, 2017; Craig & Strivens, 2016).

Finally, more than half of the account holders did not present identities other than their dementia diagnosis, suggesting that these account holders could be using Twitter specifically for dementia activism, rather than general social contact. Despite this, it is still important to consider all aspects of identity that people choose to present. There has been a tendency for Twitter researchers who have examined health conditions to focus only on the diagnosis and not the other identities of account holders that co-exist with the diagnosis (e.g. parent, spouse, etc.; Page, 2012). Future research on the use of social media by people with health conditions, including dementia, must recognise the complexity of online identities and resist the temptation to reduce account holders purely to their diagnosis.

Limitations

Although this study has demonstrated that people with dementia are active on Twitter, it does have some limitations. Firstly, Tweetcatcher uses Twitter's Search API, which only has access to a limited index of tweets and focuses on relevance, rather than completeness (Twitter, 2017b). Consequently, it is possible that not all account holders with dementia were identified and so the findings might not be representative of the total population of Twitter account holders who identify themselves as having a diagnosis of dementia. The Search API is, however, commonly used in Twitter research (e.g. Berry et al, 2017; Hemsley et al, 2015; Harris, Mueller, Snider, & Haire-Joshu, 2013; Hemsley, Palmer, Goonan, & Dann, 2017). Tweetcatcher is also one of the most appropriate freely available data extraction tools (Brooker, Barnett, Cribbin, & Sharma, 2016) and has been estimated to capture 74% of tweets (Ahmed & Bath, 2016). Although costly to use, future research could overcome this limitation by using Twitter's 'Firehose' Stream API to access 100% of tweets over a given period of time.

Secondly, this study only included Twitter accounts written in English and account holders who mentioned their dementia diagnosis in their 'bios', so the findings may not be representative of people with dementia who tweet in a language other than English or those with dementia who do not disclose their diagnosis in their profiles.

Finally, this study focused only on the profile information of account holders and did not examine the content of their tweets. As noted earlier, research examining the tweets of people with dementia could provide insight into how people with dementia use Twitter.

Conclusion

This study clearly shows that people with dementia, with varying demographic characteristics and a range of dementia diagnoses, are active on Twitter. The majority of account holders reported 'living with' dementia, considered themselves dementia activists, or were affiliated with dementia organisations, suggesting they could be using Twitter to facilitate an advocacy role. This finding is also supported by the absence of identity information beyond a diagnosis in more than half of account holders 'bios'. Future research could examine the profiles of people with dementia who tweet in languages other than English and those who do not disclose their diagnosis in their profiles. An analysis of the tweets of people with dementia would provide insight into how and why people with dementia use Twitter.

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